

## Impact case study (REF3)

<b>Institution:</b> University of South Wales		
<b>Unit of Assessment:</b> 3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
<b>Title of case study:</b> Improving the lives of individuals at risk of Alcohol Related Brain Damage		
<b>Period when the underpinning research was undertaken:</b> 2015-2019		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b> Prof Gareth Roderique-Davies; Prof Bev John	<b>Role(s) (e.g. job title):</b> Professor of Psychology; Professor of Addictions and Health Psychology	<b>Period(s) employed by submitting HEI:</b> GRD: 2000 - present, BJ: 2005-present
<b>Period when the claimed impact occurred:</b> 2018 -2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<b>1. Summary of the impact</b> (indicative maximum 100 words)		
<p>Alcohol Related Brain Damage (ARBD) is an under-recognised condition that is associated with debilitating cognitive and physical deficits. Since 2015, the Addictions Research Group at the University of South Wales (USW) have been conducting research to improve accurate identification, assessment and treatment of the condition. Their work has underpinned the Welsh Governments' Substance Misuse Treatment Framework (SMTF), and the recommendations therein. Subsequently, the SMTF was used to inform the development of the UK SMTF. The research has also been endorsed by the Royal College of Psychiatrists in Wales and influenced professional practice and staff awareness of ARBD in The Pobl Group (the largest not-for-profit Housing Association in Wales, employing 2000 staff who support 10,000 individuals at risk of ARBD), via a training and information programme. As a result of the programme, 86% of staff members now report increased awareness of ARBD and confidence in supporting individuals with the condition.</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words)		
<p>Wales is at the forefront of legislating health-related protections and treatment frameworks within the UK. South Wales has a high prevalence of alcohol misuse with 1 in 20 deaths attributable to alcohol. As such, the Welsh Government has prioritised the issue of alcohol misuse and the associated cognitive and physical issues which accompany it. ARBD can often result in misdiagnoses such as early onset dementia. In 2014, Public Health Wales identified a need to address an absence of evidence and understanding around the condition of ARBD and subsequently approached Professors <b>Roderique-Davies</b> and <b>John</b> who were optimally positioned to address this need due to their expertise in substance misuse and addictions. The subsequent internationally innovative research, conducted by the Addictions Research Group of USW which is headed by <b>Roderique-Davies</b> and <b>John</b>, has established the prevalence of this condition, clarified the ways in which it is diagnosed, and identified the barriers to effective treatment.</p>		
<b><u>Study 1: Establishing accurate prevalence and service provision need</u></b>		
<p>Despite being a global issue, no reliable evidence of ARBD prevalence previously existed, as prior prevalence figures have been based on post-mortem data or estimated from diagnoses of the alcohol-related neurological disorder, Wernicke-Korsakoff syndrome. The USW Addictions Research Group conducted a large-scale, representative, prevalence investigation on data obtained from a diverse sample of 60 health and social care services within South Wales over a two-year period (2017-18) <b>[R1]</b>. The findings, published in an international journal, constitute the most accurate prevalence figures currently available for ARBD worldwide, providing a generalisable example to other regions and countries experiencing similar levels of alcohol use, both within the UK and beyond. The research highlighted inconsistencies in diagnostic practises and historic issues with awareness of ARBD and record keeping accuracy. A prevalence rate of at least 34 individuals per 100,000 was calculated in South Wales.</p>		
<b><u>Study 2: Facilitating early detection and diagnosis of ARBD</u></b>		

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Having identified discrepancies between approaches to screening for ARBD, and aware of the need for a uniform and systematic approach to ARBD diagnosis, **Roderique-Davies** and **John** spearheaded two investigations to facilitate addressal of these shortcomings:

**Investigation 1:** Between March 2016 and August 2018, the USW Addictions Research Group conducted a large systematic review of the research literature on neurocognitive testing for ARBD [R2]. The research highlighted:

- That conventional tests utilised in ARBD diagnosis possessed limited or absent psychometric qualities necessary for the accurate assessment and monitoring of ARBD.
- A need to move from discrete diagnosis of alcohol related conditions towards an inclusive diagnostic conceptualisation of ARBD that recognises the diversity of presentation of symptoms.

**Investigation 2:** In 2017, the USW Addictions Research Group conducted a clinical evaluation of two neurocognitive tests commonly used to assess ARBD. The research was conducted on a mixed sample of 58 individuals: 28 participants with ARBD and 30 alcohol-dependent individuals without ARBD [R3]. The research highlighted a need for clinicians to combine these assessment methods with others before reaching diagnostic conclusions, to ensure the risk of falsely identifying individuals as suffering from ARBD was minimised.

### **Study 3: An exploration of current treatment practise in identification and treatment**

**Roderique-Davies** and **John** identified an inconsistent approach to treatment across services providers, due to the absence of an adequate treatment model for ARBD. Therefore, to inform professional practise, in-depth interviews were conducted in 2018 with 17 key clinicians and health professionals involved in supporting those with ARBD within Wales [R4]. Systematic analyses of interview transcripts highlighted:

- Challenges associated with **1)** A lack of understanding of ARBD and the services and specialities responsible for treating this population **2)** A lack of resources **3)** Behaviours exhibited by ARBD sufferers that create additional stigma.
- For treatment to be effective it needed to encompass a comprehensive assessment process and individualised treatment programmes with coordinated input from multiple services.

### **3. References to the research** (indicative maximum of six references)

[R1] Heirene, R.M., Roderique-Davies, G.M., Angelakis, I. & John, B. (2020) Alcohol-Related Neurocognitive Disorders: A Naturalistic Study of Nosology and Estimation of Prevalence in the UK. *Journal of Studies on Alcohol and Drugs* 81(5), 584-594

[R2] Heirene, R. M., John, B., & Roderique-Davies, G. (2018). Identification and Evaluation of Neuropsychological Tools Used in the Assessment of Alcohol-Related Cognitive Impairment: A Systematic Review. *Frontiers in Psychology*. 9:2618. DOI: 10.3389/fpsyg.2018.02618

[R3] Brown, P., Heirene, R. M., Roderique-Davies, G., John, B., & Evans, J. (2019). Applicability of the ACE-III and RBANS cognitive tests for the detection of Alcohol-Related Brain Damage. *Frontiers in Psychology*, 10:2636. DOI: 10.3389/fpsyg.2019.02636

[R4] Heirene, R., John, B., O'Hanrahan, M., Angelakis, I., & Roderique-Davies, G. (under review Nov 2020). Professional Perspectives on Supporting those with Alcohol-Related Neurocognitive Disorders: Challenges & Effective Treatment. *Alcoholism Treatment Quarterly*

### **Funding**

Roderique-Davies, G, May, R. & John, B. Welsh Government/European Social Fund/The Pobl Group KESS Maxi funding. Screening and intervention for individuals with Alcohol-Related Brain Damage. £54,000 (April 2020)

John, B. & Roderique-Davies, R. USW/HEFCW Strategic Research Impact Fund. Impacting the lives of individuals at risk of Alcohol Related Brain Damage: improving care through implementing research findings £50,000 (July 2019)

Roderique-Davies, G & John, B. Welsh Government/European Social Fund/The Pobl Group KESS Maxi funding. Alcohol-related brain damage in Wales: An investigation of prevalence and the evaluation of a pilot supported housing project intervention. £54,000 (April 2016)

John, B & Roderique-Davies, G. USW Science & Health Research Institute funding. The development and evaluation of a screening tool for alcohol-related brain damage; £10,000 (March 2015).

#### 4. Details of the impact (indicative maximum 750 words)

**Roderique-Davies** and **John's** research indicates that ARBD has a prevalence rate four times greater than that of Motor Neuron Disease, yet just 16% of sufferers are diagnosed within their lifetime, with many cases attributed to early onset dementia and individuals consequently consigned to care facilities. With abstinence and simple treatment, approximately 75% of individuals with ARBD can make at least a partial recovery. Given that dementia care cost is in the region of £600-£1,200 per week, the potential financial impact following successful identification and treatment of just a single patient is already significant.

##### 1. Policy Impact:

As a result of their contribution to ARBD research, in May 2018 **Roderique-Davies** and **John**, along with their doctoral student Mr Rob Heirene, were invited to join the Project Board for the Welsh Government's Substance Misuse Treatment Framework for alcohol-related brain damage (ARBD) by the head of Public Health Wales' (PHW) Substance Misuse Programme. They collectively, alongside USW Visiting Professors and leading clinicians in the field, co-authored the first ever Welsh Government's Substance Misuse Treatment Framework (SMTF) for ARBD [S1]. The purpose of the SMTF is to inform and assist health and social care planners and providers to design and deliver high quality, sustainable and equitable prevention and treatment services for those at risk of ARBD. Findings from the research conducted by the USW Addictions Research Group have been used to underpin the Welsh Government's SMTF and the recommendations therein. PHW states that *"The work performed by the University of South Wales ... [was] crucial to the development of the Welsh Government SMTF for alcohol-related brain damage"* [S2]. The Welsh Government's SMTF is in the final stages of sign off by the Health Minister but is already achieving impact on policy formation in Wales. The Welsh Government's Substance Misuse Delivery Plan (2019-2022) [S3], which makes reference to the body of work by USW, has a specific action to *"Work with PHW to publish the Alcohol Related Brain Damage SMTF and then implement the findings with the aim of ensuring timely diagnosis and referral, through clear care pathways, to specialist assessment, treatment and rehabilitation services with the support of an identified lead ARBD clinician within each LHB area in Wales"*. (LHB refers to Local Health Boards, the Wales equivalent to NHS Trusts in England). The SMTF *"puts Wales well ahead of the rest of the UK in having a set of evidence-based guidelines for clinicians and commissioners on what treatment services ought to be available to support individuals with ARBD"* (Consultant Psychiatrist and Addictions Clinical Lead) [S4].

Additionally, *"the recommendations provided within the SMTF are being used to guide the ARBD section of the UK Public Health and Departments of Health current development of UK clinical treatment guidelines for alcohol, and consequently have the potential to produce far reaching beneficial change, both for health and social care professionals and those at risk of, or already affected by, alcohol-related brain damage"* [S2].

##### 2. Professional Practice Impact

In line with recommendations of the SMTF to raise awareness of ARBD and focus on early detection by providing educational training for all professionals who may work with individuals with, or at risk of, ARBD. Roderique-Davies and John have directed the training and organisational

changes within The Pobl Group [S5], the largest not-for-profit Housing Association in Wales, employing 2000 staff who support 10,000 individuals at risk of ARBD (N.B. 'Pobl' is the Welsh word for 'people').

**i) USW researchers delivered training on ARBD to The Pobl Group staff, and increased awareness of the condition:**

**Roderique-Davies** and **John's** research into the prevalence, detection, diagnosis and treatment of ARBD has informed and underpinned the development of a training and information programme for frontline service providers who are ideally placed to identify those with/at risk of ARBD. Dissemination of the training and information programme, overseen by Senior Research Assistant Dr Rebecca Ward, began in late October 2020 and has been delivered to approximately **499 (91%)** of the staff in the Support Arm within The Pobl Group [S6]. Plans are in place to extend dissemination of the programme to the staff of the Care Arm of The Pobl Group as soon as COVID-19 restrictions allow.

The training has already produced statistically significant increases for the measures of

- Awareness of ARBD
- Identification of ARBD
- Knowledge of the signs and symptoms of ARBD
- Knowledge of the treatment options for ARBD
- Understanding of ARBD
- Confidence

**Seventy-seven percent** of staff members who undertook the training reported a statistically significant increase across all aforementioned measures. More specifically, however, **87%** of individuals reported increased awareness of ARBD, **90%** reported increased awareness of ARBD signs and symptoms and **93%** reported increased awareness of ARBD treatment possibilities, *"Before I took this training course I was unaware of ARBD. This gave me an understanding and awareness of how to recognise ARBD with my clients and how I can support them"*.

**Forty-one percent** of those who completed the training and information programme identified as having no prior knowledge of ARBD, *"I had no idea the condition existed before this training"*, with **84%** of these individuals demonstrating a subsequent increase across all measures. Of those who had some prior ARBD knowledge, **72%** demonstrated a subsequent increase across all measures, highlighting that even those individuals who have professional experience of the condition can significantly benefit from further education in the subject, *"I have new knowledge to enhance other knowledge"*, *"I had some knowledge however this course has explained it in more detail"*, *"This training should have been provided sooner!"* [S6].

Additional impact from the training and information programme includes:

- 1) A change in the attitudes of staff within The Pobl Group surrounding ARBD, with **89%** stating that their attitude towards ARBD had changed after completing the training and **83%** reporting increased confidence in supporting individuals with ARBD: *"I knew very little about ARBD so my understanding, attitude and awareness has greatly increase"*, *"I understand better the possible difficulties somebody may be having if they have ARBD and can suggest some ways we can work around these"* [S6] [S7].
- 2) Facilitation of the identification of five individuals who may potentially have ARBD, as highlighted by one individual who completed the training: *"I realise that I have at least one client who may have or be at risk of developing ARBD"* [S6][S7].
- 3) Improved understanding of the current research outcomes by The Pobl Group management and The Pobl Group key stakeholders [S5].
- 4) Ongoing dissemination of the research, with **96%** of those who completed the training stating they were "very" or "extremely" likely to talk about it with colleagues. The information provided through the course has also being incorporated into learning materials for the service users of Pobl, *"I develop qualifications for our service users and will utilise the additional resources as part of our Alcohol Awareness course to highlight the dangers of heavy drinking and the long-term impact it can have. It's great to have such up to date information at our disposal"*. Additionally, the training programme with Pobl staff appears

to be very successful in disseminating the Addictions Research Group's research into detection and diagnosis of ARBD to the general public. After the sessions were delivered, we noticed a substantial increase of visits to our website. Overall, we observed an increase from pre- to post-training of **574** unique visitors per month, indicating that more people are looking to become increasingly aware of the accurate identification and assessment of the condition [S6].

Additionally, in line with recommendations from the Welsh SMTF, the research has been used to inform clinical knowledge, externally to The Pobl Group, *"Thankfully over the past couple of years we have seen a growing awareness of the condition and...a growing understanding of how it impacts on cognitive function, amongst professionals. This increase in understanding has been down to the concerted efforts of a handful of interested groups, not least the research team at USW"* [S4]. In recognition of its importance, the Royal College of Psychiatrists has officially endorsed the ARBD training that was produced by the Addictions Research Group of USW, *"the research conducted by the University of South Wales is not only leading within Wales and the UK but the world. The ramifications of their research and the subsequent awareness raising and dissemination that followed has already had an impact, from the level of the individual up to influencing governmental policy, and this impact will likely continue to spread and gain momentum"* [S8].

#### **ii) USW research has led to changes to professional practice within The Pobl Group:**

As a result of their research into the prevalence, detection, diagnosis and treatment of ARBD, **Roderique-Davies** and **John** have worked with The Pobl Group to facilitate changes to professional practise *"The work performed by the University of South Wales [has] been critical in allowing our organisation to become pioneers within support services ... training [our staff] to be confident in identification of, and referral for, the condition ... [it has] improved our response and engagement with people at risk of ARBD, increasing awareness of referral and treatment options for ARBD"* [S5]. Improvements to engagement with the service users, regarding ARBD, is further supported by extracts from the qualitative analysis of the course, *"if there are further courses to go on, I would be very interested in doing them"*, *"It just makes us even more passionate to try and right what is what is actually going on here"* [S7].

#### **5. Sources to corroborate the impact** (indicative maximum of 10 references)

[S1] Substance Misuse Treatment Framework: Prevention, Diagnosis, Treatment and Support for Alcohol-Related Brain Damage. *Welsh Government*.

[S2] Testimonials from the head of Public Health Wales' (PHW) Substance Misuse Programme regarding SMTF UK and Wales.

[S3] Substance Misuse Delivery Plan for 2019-2022 Consultation document (2019). *Welsh Government*.

[S4] Testimonial from Consultant Addiction Psychiatrist and Clinical Lead re UK SMTF and informed clinical knowledge.

[S5] Testimonial from the Managing Director of Care & Support at The Pobl Group the development and dissemination of an ARBD training programme and associated organisational changes.

[S6] ARBD training dissemination data: Uptake of training; Results from pre- and post-training evaluations at all stages of the awareness training programme for Pobl employees; Post-training quotes; USW/Pobl ARBD website traffic.

[S7] Post-training Pobl employee qualitative interviews report

[S8] Endorsement and Testimonial from the Manager of the RCPsych.